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Discrepancy between treatment goals documentation by oncologists and their understanding among cancer patients under active treatment with chemotherapy.

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Abstract

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Conflict of Interests:

We have full control of all primary data and we agree to allow the journal to review their data if requested.

Ethical Statement

The investigation of patients involved in this study was ethically just and was approved by the University of Iowa Hospital and Clinics Institutional Review Board. This is stated within the manuscript in the methods section under the sub-heading of professional interviewers.

Conflicts of Interest: Conflicts of interest have been disclosed within the manuscript

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I was the recipient of the NIH CTSA grant number U54TR001013. This was paid to the University. There is no personal financial relationship with this organization who helped sponsor the research project. I have no further conflicts to disclose in the realms of employment, leadership, stock, honoraria, consulting or advisory roles, financial support for attending symposia or educational programs, speaking bureaus, patents or other intellectual properties, royalties, expert testimonies, competing financial interests of spouse or child, or others.

Author 2 - Seth M Maliske

No competing financial interests exist

Author 3 - Hassan Kaleem

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I have potential conflicts of interest to disclose as I serve a consulting or advisory role for several companies. These companies include the following: Genentech/Roche, EMD Serono, Novartis, Eisai, and Bristol-Myers Squibb. I have no further conflicts to disclose in the realms of employment, leadership, stock, honoraria, research funding, financial support for attending symposia or educational programs, speaking bureaus, patents or other intellectual properties, royalties, expert testimonies, competing financial interests of spouse or child, or others.

Objective/Background: Discussion of treatment goals between oncologists and patients is challenging. Patients frequently misunderstand goals of therapy. There are several methods to document goals of chemotherapy, however, are frequently not incorporated into patient charts.

Methods/Design: Cancer patients receiving their first cycle of chemotherapy were interviewed. Patients' recall of discussions with their oncologist regarding therapy intent was assessed and compared to documentation. An adjusted McNemar's test was utilized. A one-sample proportion test was used to evaluate whether the overall observed rate of discordance was significantly different from the proposed 33% rate; a rate posited as a threshold too high in the clinical sense.

Results: 207 eligible patients were interviewed. Oncologist identified treatment goals were not documented in 24.6% of cases and had to be excluded. There was not a significant difference in the directionality of discordance present. Inter-rater agreement between patient and oncologist was found to be adequate ($\kappa=0.64$). The overall rate of discordance (17.29%) was found to be significantly less than the proposed acceptable level of 33% ($p<0.01$). Upon univariable analysis, age, gender, marital and employment status were not found to be associated with discordance.

Conclusions: Discordance between treatment goals documentation and their understanding exists, indicating continued miscommunication between the patient and oncologist.

Keywords

Treatment Goals; Chemotherapy; Cancer; Cancer practice; Rural academics; Cancer; Cancer practice; Chemotherapy; Rural academics; Treatment Goals; Patient understanding

Introduction

Discussion about treatment goals in cancer patients between oncologists and their patients is always challenging and requires effective communication in order to provide compassionate patient care that respects patient autonomy. Open, clear, and frank communication by clinicians with cancer patients and their families promotes favorable outcomes, including satisfaction with care, adherence to treatment, physical and psychological well-being, and improves the patient-physician relationship (Heyland et al, 2009; Stewart, 1995; Zolnieriek & Dimatteo, 2009; Fenton et al, 2018). Several factors play a role in formulating a proper understanding of goals of chemotherapy which includes communication with one's oncologist, nurses, primary care provider, family members, and browsing online resources (Diaz et al, 2002; Rozenblum & Bates, 2013). Historically, physicians have been concerned that addressing issues related to prognosis and end-of-life care preferences may result in psychological harm to patients or families; however, research continues to demonstrate the benefits of such discussions (Enzinmer et al 2015; Trice & Pigerson, 2009; Wright et al, 2008). It is now generally accepted that patients should play an active role in decisions about their cancer treatment.

Pioneering studies in this field illustrated discrepancies regarding goal of chemotherapy between medical oncologists and their patients (Eidinger & Schapira, 1984; Mackillop et al, 1988). Since then many investigators have studied this relationship and found discordance rates range from as low as 24% to as high as 81% (Craft et al, 2005; Lennes et al, 2013; Pronzato et al, 1994; Weeks et al, 2012). The quality of treatment goal discussions and

decisions may be compromised when physicians and patients have differing goals of care in mind (e.g. cure, improving health, maintaining health, palliation) (Bradley et al, 1999; Rosenfeld et al, 2000), since goals provide the basic orientation and rationale for clinical and ethical decision-making (Kaldjian et al, 2005). Additionally, these discussions may be limited by patients' inadequate understanding of the potential outcomes of their treatments and the probabilities of those outcomes (Fischer et al, 1998; Fried et al, 2002; Murphy et al, 1994; Schneiderman et al, 1993). Addressing goals associated with such treatments may facilitate patients to express what goals they are expecting to achieve, how much suffering they may be willing to endure in order to achieve those goals, their awareness of the likely probabilities involved, and minimizing uncertainty with whether patients are making informed decisions consistent with their values (Cripe & Frankel, 2017). Oncologists have underestimated, rather than overestimated, patients' and companions perceived understanding of the topics discussed in the first visit (Eggly et al, 2012).

The doctrine of obtaining a patient's informed consent by an oncologist before administering chemotherapy is required by law and medical ethics (Michels & Cahill, 2005). It is important to document in writing when and under what circumstances the discussion about the treatment goals is conducted. These discussions continue to be missed (Blackwell & Boothman, 2007) and requiring documentation of treatment goal during chemotherapy order entry may serve as a reminder to have these relevant conversations, thus serving as a surrogate of improved communication. Electronic entry of chemotherapy treatment plans is being practiced far and wide. Use of Computerized physician order entry (CPOE) and clinical decision support systems (CDSSs) can substantially reduce medication error rates (Kaushal et al, 2003). At the University of Iowa, BEACON is the Health Link software program used to create standardized order sets for chemotherapy regimens for oncologic and non-oncologic indications. Since October of 2011 a new field was introduced by the name 'treatment goal' which had the following options to choose from: 1) Curative 2) Palliative 3) Symptoms control 4) Others. This field is currently optional, meaning that the oncologist can skip this field without triggering a warning.

This study will investigate the use of the "treatment goal" field in BEACON software, the documentation of the same in the oncologist's clinic note, and the discrepancies among adult cancer patients and their respective oncologists regarding communication and understanding of the treatment goals.

Methods

Patients:

Outpatients receiving chemotherapy at the Holden Comprehensive Cancer Center chemotherapy infusion suite and inpatients at University of Iowa Hospitals and Clinics between October 2012 and December 2014 were targeted. At this institution, informed consent prior to administering chemotherapy is obtained via written informed consent form signed by patient and oncologist. Verbal consents can be documented in the oncologist note or in BEACON. English speaking subjects 18 years or older receiving cycle 1 of chemotherapy regardless of origin or stage of cancer and able to give informed consent were included in the study. Patients on clinical trial were included as well. Patients receiving cycle

2 or higher in their chemotherapy regimen, receiving cycle 1 of a new chemotherapy drug due to hypersensitivity infusion reaction to the previous drug, or inpatients whose primary admission diagnosis was a medical complication directly or indirectly related to chemotherapy were excluded. Demographic information including age, gender, employment status, and marital status were obtained from the medical record.

Oncologists:

Twenty-three (23) oncologists across multiple subspecialties were included in the study, as outlined in Table 1.

Professional interviewers without oncology background surveyed the patients who had the initial consultation with their medical oncologist within 0 to 21 days of the start of the first cycle of chemotherapy. Institutional review board approved the study.

Data Collection:

After obtaining informed consent, a questionnaire was conducted face to face and the data was entered into an electronic database without identifiable information. The questionnaire is available in supplementary appendix 1. Questions included whether patients were informed about their cancer diagnosis, and if yes, then were they informed by their medical oncologist about the disease prognosis. Options included, 1) definitely be cured, 2) probably be cured, 3) cannot be cured, or 4) did not say if it can be cured. Responses 1 & 2 were coded as curative. The third question enquired about the patients' belief about the intent of chemotherapy and options included, 1) cure, 2) symptom control, 3) prolong life, and 4) other. They were allowed to choose multiple answers for this question. After initiating the questionnaire, Question 3 was subsequently edited to reflect the wording in BEACON (supplemental appendix). The term palliative intent is often used by oncologists which we interpreted as symptom control and/or prolong life to match the available options in the questionnaire. After obtaining the informed consent, patients' medical records were reviewed for medical oncologist intent of treatment as part of documentation in the clinic note, "treatment goal" option chosen in BEACON chemotherapy order entry, and standardized chemotherapy consent forms. The rate of use of computerized entry of treatment goals was recorded and the level of discordance between medical oncologist's intent vis-à-vis the patient's understanding was calculated.

Statistical analysis:

Given the clustered matched-pair nature of the study design, an adjusted McNemar's test using the method developed by Obuchowski (1998) to account for potential clustering effects within physicians was utilized to assess disagreements in perception of treatment goals between oncologists and patients. Though the absence of discordance is ideal, it is unrealistic. A rate of 33% discordance was posited as a threshold in which the rate of discordance is too high in the clinical sense. Though one always aims for no discordance, 33% was chosen based on rates of discordance from prior studies in which 25–81% discordance has been demonstrated. A one-sample proportion test was used to evaluate whether the overall observed rate of discordance was significantly different from the proposed 33% rate. Logistic regression models were applied to determine whether patient

sociodemographic characteristics were associated with discordance between oncologist and patient. Estimated effects of predictors are reported as odds ratios (OR) along with 95% confidence intervals. All tests were two-sided and tested at the 5% significance level. Data analysis for this project was performed in SAS 9.4, Cary, NC.

Results

A total of 216 patients were screened for the study; of these, 7 patients were excluded, including 2 with grade III hypersensitivity infusion reactions as defined by Common Terminology Criteria for Adverse Events version 5.0 (CTCAE v4.0). Two more did not sign consent for the study leaving a total of 207 patients included for analysis. Physicians documentation of goal of therapy with BEACON occurred in 57.0% of patients. Documentation of these same goals was found in 45.4% of patient charts. Therefore, of the remaining 207 patients, 56 (27.0%) did not have a documented treatment goal noted by the physician. Another 4 physician entries were contradictory leaving 147 potential patient-physician dyads for comparison. Fourteen patient surveys had contradictory entries or missing information in regards to treatment goals. In total 133 patient-physician dyads had a valid response available for analysis (Fig 1). Comparison of patient characteristics and disease site did not reveal any systematic differences between those included versus excluded. Non-documentation by oncologists was the primary reason for exclusion.

Of the 133 patients, the majority of patients were less than 65 years of age (69.9%). In total, 56% patients were women, 66% were married, and 81% were either employed or retired. Only 3.8% of patients were clinical trial participants. Table 1 illustrates the baseline characteristics of all study participants including details of cancer type.

There was not a significant difference in the directionality of discordance present ($p=0.61$, Fig 2). Inter-rater agreement between patient and oncologist was found to be adequate ($\kappa=0.64$). Furthermore, the overall rate of discordance, 17.3% (23/133), was found to be less than the proposed acceptable level of 33% ($p<0.01$). Of the total number of discordant patient-physician dyads, 56.5% (13/23) were discordant in the direction of patients identifying no cure while physicians' goal of chemotherapy was curative. This is in comparison to 43.5% (10/23) of patients understanding curative potential of chemotherapy when the physician goal was non-curative. Upon univariable analysis, age, gender, marital and employment status were not found to be associated with discordance between oncologist and patient (Fig 3, online only).

Discussion

Investigators have been evaluating the dynamic between patients' and physicians' understanding of goals of chemotherapy for decades. Despite a widening body of evidence advocating for improved patient-physician communication, misconception of goals of chemotherapy remains commonplace (Gabrijel et al, 2008; Quirt et al, 1997; Sapir et al, 2000). Mackillop et al (1988) were the first to study this relationship in depth. Since their sentinel article, several studies have expanded our knowledge of patients' understanding of their goals of chemotherapy (site sources). Several ideas have emerged to help explain this

inconsistency: 1) medical language barrier (Lennes et al, 2013), 2) poor physician communication (Weeks et al, 2012), 3) poor patient recall (Coughlin, 1990), and 4) physician reluctance to discuss prognosis (Hancock, et al 2007; Rogg, et al 2010). We investigated the relationship between oncologist documented treatment goals and a patient's understanding of these chemotherapy goals.

We found 17.3% (23/133) of patients with both early and advanced-stage cancer undergoing their first cycle of chemotherapy had inaccurate understanding outcomes of their treatment compared to their oncologist's intent. The rate of discordance was well below the acceptable rate, which we defined as 33%, and was substantially lower than rates reported in prior published studies where discordant values have ranged between 24–81% (Craft et al, 2005; Lennes et al, 2013; Pronzato et al, 1994; Weeks et al, 2012). Since the introduction of the optional treatment goal field in BEACON, it was utilized 57.0% of the time during our study. The intent of chemotherapy was only documented in 45.4% of notes in the patient chart. This may suggest preference by oncologists for documenting treatment intent at the time of chemotherapy order entry. Use of BEACON may have prompted the oncologist to have treatment goal discussion with patients.

Contrary to previous studies, the patients' understanding carried a less optimistic view of their cancer outcome compared to their oncologist. In fact, 22.8% (13/57) of patients with curable intent cancer carried an understanding of non-curative intent. In our study, age, gender, marital status, and employment status did not have a statistically significant contribution towards the discordance in treatment goals.

There are inherent patient and physician related risk factors for discordance. Many of these risks cannot be controlled for with use of programs like BEACON. As mentioned previously, physician reluctance is a barrier to patient understanding of goals of chemotherapy. Although physicians unanimously acknowledge the importance of relaying prognostic information, it is known that there remains an unwillingness to relay a grim scenario associated with end-of-life cares (Hancock et al, 2007; Rogg et al, 2010). Reasons for this hesitancy include an oncologist's fear for loss of reputation and heightened stress related to the topic (Rogg et al, 2009). Physicians associate prognostic discussions with loss of hope (Mack et al, 2007), and as such, struggle to verbalize end-of-life issues when a patient is less symptomatic and when treatment options still exist (Keating et al, 2010). This delays these conversations, which in turn, postpones proper dialogue of treatment goals. Prognostic discussions provide an ideal setting for oncologists to identify the expectations and limitations of planned chemotherapy. It can be hypothesized that use of computerized entry of the treatment goal field may prompt the oncologist to initiate a conversation to discuss prognosis and goals of therapy with the patient, similar to prompts improving use of DVT prophylaxis (Galanter et al, 2010) and indwelling urinary catheter use (Meddings et al, 2014). A study to investigate this idea can be contemplated. We encourage dedicated study to this question.

Even more, the conversations may be occurring correctly and documented correctly, however as patients cope with their new diagnosis, they may not be ready to accept the nature of their illness. A recent study reported 38% of patients with advanced cancer failed

to recall a prognostic conversation with their oncologist (Epstein et al, 2016). This inability or unwillingness to accept poor prognosis creates an atmosphere of “false hope.” False hope has been shown to be a key contributor to discordant values. Utilizing a cohort of approximately 10,000 patients with metastatic lung and colon cancer from the CanCORS study, Weeks et al revealed 74% of all patients had a misunderstanding of the treatment goals of their chemotherapy (Weeks et al, 2012). These patients were being treated with non-curative intent, yet expected a cure. In our study, 7.5% of patients with incurable disease incorrectly identified their disease as curable.

Communication with respect to cancer related treatment goals in non-native English speakers and elderly patients can be particularly challenging (Lennes et al, 2013). As our study was a single-center study performed in Iowa, with a primary Caucasian, English-speaking demographic, we were unable to control for non-native English speakers. However, we did not find a significant difference in the discordance rate between the dyads when comparing age >65 versus <65 ($p=0.59$). This may support the notion that non-native English speakers carry the greatest risk for inaccurate expectations. Further investigation into improved communication, especially in groups such as non-English speakers, should be looked at more carefully.

Limitations:

There are several limitations of our study. The use of patient survey is well-known to be associated with recall bias. To overcome this, we chose to query patients before their first dose of chemotherapy knowing patients recently had an interaction with their oncologist. We excluded patients who last seen their oncologist greater than 21 days prior to survey. However, a delay of days to weeks always exposes a risk for errors in patient recall. Another limitation related to the impact of BEACON is the assumption that ordering of chemotherapy happens before entering, or while in, the patient’s exam room. Even further, there are several factors that can still influence this concept. The oncologist can remain reluctant with sharing intent for chemotherapy with their patients by foreseeing a lack of hope or “giving up” on treatments. In addition, with the lack of oversight of the physician-patient interaction at the time of treatment goal discussion, the impact of BEACON brings forth the assumption that conversations are truly being held. Verifying the utility of treatment goal field in prompting the oncologist to have the discussion could have been ideal, however this is fraught with time-intensive limitation during a busy clinic schedule. Establishing a standardized method of patient communication in regards to treatment goal could overcome the inability to observe the patient-physician interactions, but to date there are no uniform protocols in place, which further limits this study. Lastly, it is important to note that non-documentation by oncologists was the primary reason for exclusion which introduces bias into the results. In total, 56 patients lacked corresponding physician documentation of goals of treatment. As these patients were excluded, it is assumed that no goals of care were discussed with these patients. One may propose the lack of documentation could be a proxy for the thoroughness of the oncologist not only in recording information in medical records but possibly in explaining treatment goals with the patient, as well. However, without direct supervision of the patient-physician interaction, this remains unproven. The inconsistent use of BEACON limited the number of valid patient-physician

dyads. After excluding the incomplete and contradictory patient questionnaires, we were left with 133 patient-physician dyads. Although incomplete documentation limits the power of our study, it should also be seen as an opportunity to implement universal documentation of informed consent procedures including intent of treatment to be consistent with the ASCO guidelines (ASCO Institute for Quality Informed Consent for Chemotherapy).

Implications:

Though our data illustrates the lowest current documented rate of discordance, we know 17.3% of patients misunderstanding their goals of treatment is still too high, and thus want to pursue measures that work towards a 100% concordance rate. Our prospective goal is to institute a “hard stop” in the BEACON software program, thus requiring physicians to document goals of treatment. Upon manipulation of this variable, future statistical analysis can investigate the association between BEACON and discordant patient-physician dyads.

Conclusion

Universal documentation of discussion of treatment goals by oncologists with their patients is lacking. Discrepancy still exists between documentation of goals of therapy and patients’ understanding of the same indicating ongoing lack of proper communication between oncologists and their patients. Efforts to promote utilization of computerized entry of treatment goal fields in an attempt to improve communication is advocated for future research.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Fig. 1.

Diagram illustrating reasons for exclusion from the study. No treatment goal identified indicates absence of documentation in BEACON, physician notes, and informed consent. No additional information indicates “other” selected in BEACON with no free text clarification plus absent documentation in physician notes/informed consent. While, contradictory refers to discrepancy between physician documentation in BEACON compared to physician notes/informed consent.

	Patient		
Oncologist	Yes	No	p-value
Yes	44 (33.1%)	13 (9.8%)	0.61
No	10 (7.5%)	66 (49.6%)	

Fig 2.
Directionality of discordance of inter-rater agreement between patient and oncologist was non-significant

			Odds of Discordance			
Covariate	Level	N	Odds Ratio	95% CI		P-value
Gender	Female	74	1.30	0.52	3.25	0.58
	Male	59	-	-	-	-
Married	Yes	88	2.06	0.71	5.96	0.18
	No	45	-	-	-	-
Employed	Yes	67	1.35	0.55	3.33	0.52
	No	66	-	-	-	-
Age	65+	40	1.30	0.50	3.37	0.59
	<65	93	-	-	-	-

Fig. 3.
Discordance between oncologist defined goals and patients understanding of them was not dependent on other factors

Table 1

Characteristics of surveyed patients receiving first cycle of infusional chemotherapy. *CNS: Central Nervous System, FGU: female genitourinary, GI: Gastrointestinal, MGU: male genitourinary.*

Variable	Level	N = 133	%
Age	65+	40	30.1
	<65	93	69.9
Gender	Female	74	55.6
	Male	59	44.4
Marital Status	Divorced/Separated	22	16.5
	Married	88	66.2
	Single	15	11.3
	Widowed	8	6.0
Employment Status	Employed	67	50.4
	Retired	41	30.8
	Student	1	0.8
	Unemployed	24	18.0
Clinical Trial Participant?	No	127	96.2
	Yes	5	3.8
	Missing	1	-
Site	Breast	19	14.4
	CNS	1	0.8
	FGU	22	16.7
	GI	17	12.9
	Head & Neck	12	9.1
	Leukemia	7	5.3
	Lung	18	13.6
	Lymphoma	18	13.6
	MGU	10	7.6
	Melanoma	4	3.0
	Myeloma	3	2.3
	Unknown	1	0.8
	Missing	1	-